

AMENDED IN SENATE APRIL 9, 2003

SENATE BILL

No. 231

Introduced by Senator Murray

February 14, 2003

An act ~~to amend Section 124996 of, and to add Section 124982 to,~~ the Health and Safety Code, relating to hereditary ~~disorders, and making an appropriation therefor.~~ *disorders.*

LEGISLATIVE COUNSEL'S DIGEST

SB 231, as amended, Murray. Hereditary disorders: Genetic Services Advisory Committee.

The Hereditary Disorders Act requires, among other things, the Director of Health Services to establish any regulations and standards for hereditary disorders programs ~~as that~~ the director deems necessary to promote and protect the public health and safety.

~~Existing law requires the department to charge a fee and deposit the fee into the Genetic Disease Testing Fund, which is continuously appropriated to the department for purposes of the act.~~

This bill would require the director to appoint a Genetic Services Advisory Committee with members who meet specified qualifications.

This bill would require the committee to meet at least annually to review genetic services programs and to report annually to the Legislature *and the Governor* on or before October 30 on specified topics.

~~This bill would provide that the activities of the committee shall be supported by the Genetic Disease Testing Fund, and would increase the fees collected by the department as of January 1, 2004, by \$0.25.~~

~~By increasing the amount of money deposited in a continuously appropriated fund, this bill would constitute an appropriation.~~

This bill would authorize the committee to apply for and receive federal and private funding to fund its activities. This bill would provide that the committee shall operate exclusively from these funds, and shall only operate to the extent these funds are available.

Vote: $\frac{2}{3}$ majority. Appropriation: ~~yes~~ no. Fiscal committee: yes. State-mandated local program: no.

The people of the State of California do enact as follows:

- 1 SECTION 1. Section 124982 is added to the Health and
2 Safety Code, to read:
3 124982. (a) The director shall appoint a Genetic Services
4 Advisory Committee and establish rotating terms of service for the
5 committee members.
6 (b) The committee shall consist of one or more individuals
7 affected by a genetic disorder or parents of individuals affected by
8 a genetic disorder; advocates for women and childbirth issues;
9 health care providers specializing in clinical genetics, pediatrics,
10 obstetrics, molecular biology, cytogenetics, and biochemical
11 genetics; representatives of hospital administration, the insurance
12 industry, the biotechnology industry, and genetic counseling; and
13 professional organizations representing physicians and registered
14 nursing.
15 (c) The committee shall meet at least annually and shall review
16 genetic services programs conducted under the Hereditary
17 Disorders Act ~~or regulated by the department~~, and report to the
18 Legislature and the Governor annually on or before October 30
19 with respect to all of the following:
20 (1) The availability and utilization of genetic services.
21 (2) The quality of services provided.
22 (3) The cost and funding of services.
23 (4) The need to discontinue or add additional services or
24 improve the quality, quantity, distribution of services, or provider
25 reimbursement.
26 ~~(d) The activities of the committee shall be supported by fees~~
27 ~~in the Genetic Disease Testing Fund collected pursuant to~~
28 ~~subdivision (e) of Section 124996.~~
29 ~~(e)~~
30 (d) Committee staff shall include at least one full-time position.



1 ~~SEC. 2. Section 124996 of the Health and Safety Code is~~
2 ~~amended to read:~~

3 ~~124996. (a) The Genetic Disease Testing Fund is continued~~
4 ~~in existence as a special fund in the State Treasury. The department~~
5 ~~may charge a fee for any activities carried out pursuant to the~~
6 ~~Hereditary Disorders Act, including licensing activities conducted~~
7 ~~pursuant to Section 124980. All moneys collected by the~~
8 ~~department under the act shall be deposited in the Genetic Disease~~
9 ~~Testing Fund, that is continuously appropriated to the department~~
10 ~~to carry out the purposes of the act.~~

11 ~~(b) It is the intent of the Legislature that the program carried out~~
12 ~~pursuant to the act be fully supported from fees collected under the~~
13 ~~act.~~

14 ~~(c) (1) The director shall adopt regulations establishing the~~
15 ~~amount of fees for activities carried out pursuant to the act.~~

16 ~~(2) The director shall increase the fees collected by the~~
17 ~~department as of January 1, 2004, by twenty-five cents (\$0.25) to~~
18 ~~support the staff of the Genetic Services Advisory Committee~~
19 ~~established pursuant to Section 124982.~~

20 ~~(d) The “Hereditary Disorders Act” or “act” referred to in this~~
21 ~~section is the act described in subdivision (b) of Section 27.~~

22 ~~(e) The committee may apply for and accept federal funds for~~
23 ~~the purpose of funding the activities of the committee. In addition,~~
24 ~~the committee may accept gifts and donations from any source,~~
25 ~~including individuals, philanthropic foundations or~~
26 ~~organizations, corporations, or corporate endowments. The~~
27 ~~acceptance and use of federal funds, gifts, or donations may not~~
28 ~~entail any commitment or pledge of state funds, nor obligate the~~
29 ~~department to continue the programs or activities for which the~~
30 ~~federal funds are made available. The committee shall operate~~
31 ~~exclusively from private and federal funding and shall only~~
32 ~~operate to the extent these funds are available.~~